

Not Quite Abled and Not Quite Disabled:
Experiences of Being "In Between" -
ME and The Academy

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ME and the Academy

I fell ill several years ago and three physicians wrote letters to support my illness.¹ The diagnosis was *Myalgic encephalomyelitis*, or ME (popularly known as Chronic Fatigue Syndrome or CFS). ME is a disease of the central nervous system with an indefinite aetiology. Symptoms include pain, fatigue, and cognitive impairment and the course of the disease progress is unpredictable. Recovery rates vary with a full recovery estimated at less than three per cent. The disease predominantly affects women.

I was not sure how to arrange my life academically so that I could be ill and get tenure so that I could keep my job. My job as a faculty member both permitted me to have time to be ill and circumscribed the range of choices I had for recovery. Initially, I went on short term sick leave. As part of the agreement for getting sick time off during the term, I had to prepare the rest of my lectures for the term and put together my reappointment dossier. I also chose to stay in contact with some graduate students and to continue organizing an international conference about feminist praxis. In exchange the university paid me while I was sick and agreed not to contact me at home on routine matters. With this agreement in hand and my work for the term complete, I went home to collapse completely.

Several months later, still with severe symptoms (what was I thinking?), I returned to the university on a reduced workload, one that, again, I had to negotiate with the administration. There was no policy that dealt specifically with chronic illness. Short term sick leave, for up to six months, applies primarily to acute illness and increasingly to situations for stress, both with relatively short recovery periods. The long term disability policy relates to injuries and illness that *fully* prevent someone from completing their work tasks for long periods of time. The very idea that I could do some of the work tasks, but not all of them and that I could complete most of my work tasks, but not during specified times or in designated spaces, seemed to be outside the purview of policy and the experience of university administrators. With my short term sick leave used up, I considered long term disability benefits (LTD). But, because I had not been *completely* off work the six months prior to applying for benefits, I had to negotiate my re-entry into the academy on an individual basis.²

These sets of experiences – the withdrawal from the academy, the negotiation of terms to return full-time to the academy, and the period between these two events – led me to think through how being in between ability and disability, in between health and illness, in between employed and unemployed restructured the ways I related to pursuing a career as a faculty member in the academy. Although I reacted immediately to this restructuring, only now am I beginning to figure out why and how I responded. My ongoing readings in feminism and poststructural theory continually frame and re-frame my experiences and enhance my fascination with what is between ME and the academy (e.g. Diprose 1994; Davis 1997; Thomas 1999).

In the first half of this paper, I explore how to think about spaces in between ability and disability. In the second half, I provide an analysis of some of my own experiences between ME and the academy. I close with comments on how to frame workplace accommodation strategies and actions that could incorporate the uncertainty and ambiguity of a chronic illness like ME.

In Between Spaces

Within the academy, faculty members³ with chronic illness could be said to fall between the cracks. We have to recover in six months, or not recover at all. We have to work completely or not to work at all. We have to be fully abled or fully disabled. To fall between the cracks really means that there is no category for a person with chronic illness to fit in. We are neither fully abled nor fully disabled. We could be described as both partially abled and partially disabled. But most often we are cast as not quite abled and not quite disabled, somewhere in between the *distinguishable* spaces of ability and disability. "Falling between the cracks" reminds me of the extent to which academic institutions are ensconced in binary thinking. Once designated as "between the cracks," there is nothing more for the institution to do except to negotiate terms of employment individually.

Yet there is no other place to be with chronic illness, except to exist between those cracks. (And, oh, how those cracks are contoured!) One of the conceptual difficulties arising out of this crude categorization is the non-recognition that there is anything between one category and another, between an absence or a presence, between nothing and something. That there is nothing – the "between the cracks" – is indeed something – *in between spaces*! If we understand being in between spaces as something or somewhere, then being there might matter to who we are. If so, then theories of difference can be useful in figuring out how to link in between spaces with other types of spaces and to think about how we adjust to living in between spaces, as not quite abled and not quite disabled.

Mouffe (1995) uses Derrida's concept of "constitutive outside" to explain the relationship between self and other. Two basic premises underlying the notion of the "constitutive outside" are: (1) any identity of a "we" is based on excluding some "other" and (2) subject positions are constituted through sets of social relations. When thinking about how difference is (re)produced, Mouffe points out that within the same identity of "I" there is always some remnant of that which is being excluded, even if it is only its absence. Thus, while identities are being constituted, there is already an inclusion in some form of the "outside." In this way, no person can attain a complete, permanent, singular identity for there is always already present some "other." For example, when defining a person with ME as disabled, there is already implicated in that identity the notion of ability. Similarly, in defining a person with ME as able-bodied, being disabled is excluded.

Mouffe goes on to argue that because identities are constituted, there is no specific identity that is not open to challenge because there is no self-referential point that is outside the process of constituting difference. In this sense, persons with disabilities are able-bodied in some ways just as able-bodied people are disabled in other ways. In the context of linking identities or creating a "we," this non-specificity of identity means that there is no definitive or predetermined link to or with other people (Mouffe 1992). Any connection is partial and in flux. This, however, does not mean that we cannot be part of a collective identity or a group of people with ME. Mouffe (1992) uses the term *nodal point* to describe temporary fixations around which identities coalesce. Nodal points result from hegemonic processes through which identities come to be conceived as tightly defined, fixed, and natural. Disrupting these nodal points can help in transforming identities from a static, politically immobile set of associations to a dynamic, politically mobilizing set.

Mouffe's theory of differentiating identities is useful in understanding being in between spaces while living with chronic illness. She says that even though identities are fluctuating, indeterminate, and conditional, they can become fixed through the ways power is deployed in society. So, even though ME is a contingent identity for anyone (because even among persons with ME, identities are not unitary or monolithic), we still take on the fixed identity of being "not quite abled and not quite disabled." For understanding ME, what might be useful is unravelling the processes that constitute a particular nodal point - de-linking the identity of ME as *neither* abled *nor* disabled - and re-activating it - constituting ME as an

identity that is *both* abled and disabled. Rather than differentiating a disabled body from an abled body, we can embrace oppositional binaries that move us counter hegemonically toward a new way of defining ourselves as a body that is abled and disabled *at the same time*.

Volatility Within In Between Spaces

This explanation of how identities form aids in articulating how we can be active in rethinking identities in a way that more closely corresponds to experiences of chronic illness. Because the basis of identity is conditional on numerous sets of interactive social relations, individual and singular experiences are not excluded within a collective identity. They are also not the defining element of a particular identity, as for example, in what can or cannot constitute what it is to be abled or disabled. The identities themselves become *volatile* – volatile in the sense of being ever changing, unpredictable, fluctuating (after Grosz 1994). Such volatility opens up multiple ways to think about how illness and ability connect.

What poses problems in the academy is that this volatility as part of in between spaces is not part of the way administrators approach faculty members who have chronic illness. Volatility from the institution's point of view translates into unreliability, capriciousness. This has an added dimension in that an institution based on serious thinking cannot be expected to support a superficial, frivolous, erratic academic who is *unable* (used deliberately in this context) to think seriously. Any set of accommodating arrangements is routinely characterized as “self-serving” and preferential for the person with chronic illness. As a result, any success that an individual with chronic illness achieves is not her own. Success can only be attributed to the advantageous situation that a person with chronic illness was able to negotiate individually, often interpreted as at the expense of her colleagues.

In order to illustrate how Mouffe's thoughts about how identity forms play out through divergent views of volatility, I draw on three experiences of engaging with administrators in my university over negotiating spaces in between ME and the academy.

Negotiating Illness

One of the most common misunderstandings about ME within the academy among faculty members is that ME is not all that serious an illness. The message we get over and over again is the “quicherbitchin⁴ and get on with it” or the “after all we're all tired” attitude. So it really came as no surprise that when I went to the Chair and told him that I would have to go on sick leave immediately, he expected me to prepare for being ill. Illness and the inability to work are associated (hegemonically) with more acceptable illnesses from which one eventually recovers, as for example, acute illness, hospital stays, and some mental illness. These associations form a specific nodal point that over time has been naturalized – serious illness is the only reason not to be able to work. By implication, any illness that is not serious cannot be a legitimate enough reason to be off work. Thus, requesting sick leave because of ME throws into turmoil the existing taken-for-grantedness of the link between illness and the ability to work. More pointedly, the legitimacy of being ill is being challenged, a challenge with dire material consequences.

Because chronic illness is a non-category and not part of the “naturalness” of the experience of being on sick leave, administrators expected me to “plan” for being ill. Before I was permitted to be sick *institutionally*, I had to complete a specific set of work tasks, ones that would have never been expected from someone who just had a heart attack.⁵ I was forced into a “negotiation of illness” because I am not part of the pre-existing categorization of people who are ill and can be off work. Because I “fell between the cracks,” I had to do more work at a critical time of my illness in order to make my leave based on sickness acceptable and legitimate.

This negotiation of illness also provides an example of the way in which volatility

is used against a volatile body. Chronic illness, generally, and ME, specifically, are not conventionally accepted as serious illness, although some chronic illness is more acceptable.⁶ My ability to go to school and announce my illness to administrators suggested that I was able to work, but preferred not to. The unpredictability of ME did not permit me to make a public to-do over my collapse. By not embracing volatility and the way it works, the administrators in the university could only slot me into pre-determined, fixed categories – if I could work, I was not sick; if I were sick, I could not work. So, when I completed the tasks that were demanded of me, the administrators called my ill identity into question precisely because I was able to complete the tasks!

Long-term Disability Insurance Benefits

For two years, beginning Spring 1996, I negotiated a workload with a reduction in teaching and administration.⁷ Near the end of the two year period, administrators told me that I had to apply for long-term disability benefits. LTD policies, as administered by benefits analysts, have excessively narrow definitions of disability in the context of chronic illness. Key is the requirement that a person has not completed any work task at all in the prior six months. If so, then s/he is disqualified for benefits. With some companies, partial claims are possible. In my case, a representative of the university advised me to apply for full benefits.

What is at issue here in this example is the inflexibility of categories of identity and the insistence of the university to apply for LTD. First, LTD has only two identity categories – abled and disabled, with nothing in between. Designation by an LTD analyst of a employee as only either abled or disabled does not permit an identity other than a “naturalized” category of (dis)ability. This designation also denies alternative forms of work expressions and imposes a specific model of a worker. Such a categorization is based on the notion that ability implies an exactness of time and space to accomplish specified work tasks.

Other modes of working are ignored. For example, the complexity and volatility of living and working with ME refashions what it means to be exact. Lectures, meetings, and office hours often depend on a physical presence. Yet for persons with ME, a physical presence in a location other than home may mean that afterwards there is a two day bed-ridden recovery period. Throughout the period between taking sick leave and returning to work full-time, I had been able to restructure the way I work so that I could do a wide range of tasks in ways that did not exhaust me, did not demand my physical presence, and did not require me to spend excessive amounts of time interacting. I clearly experienced work time and space quite differently than my colleague next door. Yet policy-wise, this was not a possibility. I could only exist in between the categories of abled and disabled because of the inflexibility of the workload for a faculty member in a university.

Second, the university administrators knew that I had been working part-time for the preceding two years and still insisted that I apply for full LTD benefits. Knowing that I would not fit into the disability category, university administrators set me up to fail the examination while at the same time being justified to demand my return to work as a full time faculty member. They drew their credibility from the internal consistency with their own set of criteria for figuring out how to determine what it means to be disabled – depending on parameters set by an insurance company. The refusal of my claim by the LTD insurance company legitimated their assertion that I was abled-bodied which further ensconced the nodal point where only certain types of illness could be identified with the inability to work. This manoeuvre separated my corporeal body from its possible categories, denied my volatility, and set me up as an able-bodied worker who was, institutionally, no longer ill.

Re-Entry Into “Full Time” Employment

Once the benefits analyst from the insurance company refused my application for LTD, university administrators used this opportunity to declare the institution’s position with

regard to what is health and what is (legitimate) illness. I raised the possibility of making a partial disability claim because of my disqualification. Administrators countered with the declaration that *all* such arrangements had been made *only* when the person was found to be *fully* unfit to work at all. Whether this is the case or not is not the point. The point is that the one policy that could possibly incorporate chronic illness into a reasonably fair accommodation package sets out – from the beginning – to differentiate partial and full disability benefits on the same terms – only for the fully disabled!

This exclusion of chronic illness, particularly those marginalized within the criteria set up within the LTD insurance structure, permits university administrators to assign institutional labels to employees. For me this played out in two interrelated ways.

First, because of the fixed definitions of ability to work, individuals who are in neither one category or another become subject to varying social inscriptions of chronic illness including such derogatory labels as hypochondria, hysteria, and “something in her head.” In my case, another implication was that I was not a “team player.” My unpredictability disrupted my workplace because planning for my illness and taking sick time from the institution’s viewpoint are based on an either/or situation – either sick or well, either abled or disabled – and not from a position where an individual can be both – both sick and well, both abled and disabled. If I were a “team player,” then I would take up my full load; I would no longer be ill; I would join the ranks of predictability. The administration’s view was that I was playing the system to my own benefit – being able to get full pay on a reduced workload – and not being fair to my co-workers. There was no acknowledgement that I exist in between spaces; no recognition that my identity as “not quite abled and not quite disabled” would never be legitimate.

Second, because individuals do not fit neatly into categories created by authority figures in health fields, university administrators tend to blame the individual with chronic illness for systemic problems. In my case, this blame spawned the notion that I was neither good at being ill, nor good at being healthy. If I were good at either, then the administration could more easily “settle” my case. Being sometimes ill and sometimes healthy poses dilemmas for workload issues – paramount in the academy – that the administration is reluctant to resolve for fear of setting a precedent. Equality, (supposedly) the basis upon which workload tasks are assigned, is difficult to achieve when someone cannot perform work tasks in the predictable manner. There is a presumption that one can not be “equal” with a restructured workload, one that is designed *with* an individual with chronic illness so that tasks are achievable bits in both time (deadlines, schedules) and space (location, presence).

Together these institutional labels shaped the way I re-entered the academy “full-time.” At the same meeting with the discussion about the refusal of LTD which included the declaration of the definition of health and illness, university administrators were adamant about classifying me as full-time prior to my research leave in Summer, 1998. The argument the administrators presented at that time was that they would like to see me get full sabbatical pay. Obviously, this was surprising given that we had been discussing full-time status with regard to specific work tasks. Bearing in mind this discussion, which was immediately prior to the suggestion, I countered with declaring my status full-time from the end of term onward. I argued that because my work tasks would not change significantly between then and the day my research leave would begin, I would prefer that my status be full-time on the basis of workload and not salary considerations.

This experience demonstrates how easily full-time status can be de-linked from a faculty member’s ill identity with workload implications and re-sorted into a financial category for administrative ease. Once it was clear that I fell between the cracks financially, university administrators needed some justification to push me up one side of the chasm into a *distinguishable* space – one of full-time status, through which I could instantaneously transform into being “fully-abled.” There was need no more to think about restructuring a work-

load to accommodate a partially abled, partially disabled body. They could forget about me as a “problem” and desist from blaming me for not “fitting in.” The implication with full-time status was that I could finally be good at doing something, being healthy institutionally.

Framing Strategies Toward Accommodation

A fundamental question arising from this narrative is: if we can find a way theoretically to re-constitute an identity in between the spaces of ability and disability as being both abled and disabled, then how can we politically mobilize this reconstituted identity as a site of praxis in the academy? My problematization of this specific set of experiences I have had in the academy indicates that the difficulty in mobilizing reconstituted identities lies not in the re-constitutive process, but rather in the mobilization of a *particular* re-constituted identity – that of “not quite abled and not quite disabled.” For a collective praxis, one that challenges the institutional convenience of negotiating illness individually, activists in the academy could usefully frame strategies toward accommodation in volatile terms.

If the connection between being ill and being able is fleeting, then chronic illness can be re-defined as within the realm of the expected. Volatility can become more routine; not in the sense of predictability, but in the sense of being expected as a possibility. In order to get to a place of accepting chronic illness in its own pattern of fluctuation, accommodation strategies need to be flexible. This flexibility has to be in terms of the chronic illness itself as well as the variability in disease activity. Various types of chronic illness manifest differently; therefore, the specificity of accommodation strategies must look different. Episodic flare-ups with Rheumatoid Arthritis need to be accommodated differently than the ongoing managed chronicity of Lupus. For persons with ME, disclosure may not be a viable strategy because of the negative associations with the illness. However, with diabetes, heightened awareness can be necessary for survival. For persons with Multiple Sclerosis, it may be easier to get a wrist support for the computer or full-spectrum overhead lighting than a home computer or equipment to lecture over closed-circuit television, even though all may be necessary for the faculty member to accomplish her tasks.

Accommodation strategies also need to be re-defined such that there is less a sense of a norm against which a person with chronic illness is measured and more a notion of equitable access to the work involved with a faculty position. In this way, academic activists can more effectively dispel the association of accommodation with being the route to “E-Z street.” Granted, much policy within disability accommodation is rooted in these terms. What is missing is the connection to volatility. Embracing volatility in policy opens up possibilities for re-framing accommodation as a process of enabling an environment such that the range of tasks associated with a particular job can be completed not only within the distinguishable spaces of ability and disability, but also in between spaces. Re-constituting identities through taking up the concept of volatility can only enhance the capacities of persons with chronic illness in a world that values “health” and “ability.”

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Endnotes

1. For the institution, two physicians had to provide information to support the request for sick leave. I obtained a third because only one had provided a diagnosis.

2. Although the university would cite this as “individual” negotiations, my case was far from being an individual effort. Lawyers, healthcare professionals, and on-campus

advocates assisted me in my negotiations by providing documentation, advice, and support. I thank them all, especially Judith.

3. I prefer to limit my discussion to faulty members within the university. I know that persons with chronic illness, including ME, face similar situations especially when it comes to dealing with institutions. However, the points I want to make may be specific to white female faculty members and may only be extrapolated to other persons with ME in other employment positions through problematizing experience in ways that deal critically with insights gained from having chronic illness including ME and being employed in the academy.

4. This has particular gendered implications because it is women who bitch and complain, not men.

5. I am not saying that chronic illness is more important than acute illness. I am also not saying that people who have just had heart attacks should be "planning" to be ill. The issue is about legitimacy and processing authority.

6. For example, diabetes, arthritis, and heart disease as chronic illness are much more socially and biomedically accepted than ME.

7. Systemic harassment against women and feminists in my work environment complicated my return to the university. I do not think that I would have been as "ill" as I was in 1995 if I had been in a non-hostile work environment. Nor do I think that I would be as "healthy" as I am now if I would have been forced (institutionally) to return to that environment. I know that I am doing injustice to the intricate connections among illness and work environments in this text primarily because I have yet to work through those particular connections in the context of theories of difference and identity and of body politics.

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